Tools for Testing Decision Making Capacity in Dementia

ABSTRACT

Background: Dementia is a common cause of altered decision-making capacity. Determining whether an individual has the ability to make a specific decision can be very challenging for both clinicians and researchers. UK legislation requires that we both promote residual capacity where possible, and protect vulnerable adults who cannot make independent decisions. We evaluated published instruments designed to aid in the assessment of capacity, focussing on those meeting UK legal requirements. We also consider further disease and culture specific factors which may influence decision making.

Methods: A search of electronic databases was made for articles published between 2000 and 2017 detailing structured tools for the assessment of mental capacity. These were evaluated against UK legal requirements.

Results: Nine tools were identified which fulfilled UK legal requirements. Their design and structure varied, as did the level of reliability and validity data available. Some instruments can be tailored for a specific decisional scenario, whilst others are designed for use by particular patient groups.

Discussion: A wide range of mental capacity assessment instruments are available, but not all fulfil UK legal requirements. Healthcare professionals and researchers should be mindful of personal, cultural and disease specific factors when assessing capacity. No gold standard for capacity assessment exists, which hampers the evaluation of different approaches. A combination of the opinion of a healthcare professional or researcher trained in capacity evaluation, plus the use of a structured assessment tool is the most robust approach.

Key words:

Mental capacity | Informed consent | Incapacity

Dementia | Decisional capacity

Key points:

People with dementia should not be assumed to lack decision making capacity.

UK legislation sets out clear requirements for the presence or absence of capacity.

Multiple tools exist to aid in the assessment of decision making capacity.

Expert opinion and structured assessment can optimise the assessment of capacity.

Word count (excluding boxes and tables): 3000

Introduction

Dementia now affects tens of millions of people worldwide. The majority affected are older adults, who experience progressive cognitive decline. Mental capacity is one of the greatest ethical and legal dilemmas surrounding the care of people with dementia, who are often assumed to be unable to make informed decisions. However, a dementia diagnosis does not automatically equate to incapacity. Clinicians and researchers are frequently asked: Is this individual able to provide informed consent? There is a clear need for professionals to make accurate and reliable decisions regarding capacity, preferably in a standardised manner. This is vital to promote the autonomy of people with dementia, and to protect those who have lost decisional capacity. Here we review the UK legal framework for defining mental capacity, and published capacity assessment tools.

Mental Capacity: UK Legislation

Legal definitions of mental capacity vary internationally; in the UK, three separate pieces of legislations apply: the Adults with Incapacity (Scotland) Act 2000[1], the Mental Capacity Act 2005[2] for England and Wales, and the Mental Capacity Act (Northern Ireland) 2016[3]. Whilst these are separate legal entities, their fundamental principles are very similar.

Box 1. Principles of the Mental Capacity Act 2005 and the Adults with Incapacity (Scotland) Act 2000.

The five key principles of the Mental Capacity Act 2005:

- Capacity is presumed unless proven otherwise
- All practical steps to help a person to make a decision must be taken
- An irrational decision does not equate to the absence of capacity
- If a person lacks capacity, any decisions made must be in their best interests
- Any decision for an adult lacking capacity made must be the least restrictive option available for their basic rights and freedoms

Requirements of the Adults with Incapacity Act regarding decisions taken on behalf of an adult lacking capacity:

- Decisions must be in their best interests.
- Decisions must take account of their wishes, so far as these are known.
- Decisions must take account of the views of relevant others.
- Decisions must restrict freedom as little as possible while still achieving the desired benefit; and encourage the adult to exercise residual capacity.

The N.Irish legislation[3] also requires that capacity be presumed to be present, that all practical help and support must be provided to support decision making, and decisions taken on behalf of an adult lacking capacity must be in their best interests.

Capacity is decision specific and should be assessed on this basis. It may also vary over time (including over the course of a single day).

Box 2. Criteria determining a lack of capacity (note the presence of any one factor indicates a lack of capacity).

- They cannot understand information relevant to the decision.
- They cannot retain information for the time required to make the decision.
- They are not able to appreciate the relevance of the information or to use and weigh that information as part of the process of making the decision.
- They are not able to communicate a decision (whether by talking, using sign language or any other means)

Information must be provided in an appropriate format, which may mean using simplified language, visual aids or other communication means. Capacity is assessed on the process of decision making rather than the content of the decision itself, and under UK legislation that decisions do not have to be rational, reasonable, or logical.

Capacity and legal affairs

Capacity is particularly relevant in the context of Power of Attorney (PoA), Guardianship, voting, contracts, wills, marriage and criminal responsibility[1–3]. In the UK, individuals must have mental capacity to set up (or revoke) a PoA. A PoA allows an individual to appoint a chosen person(s) to make financial or welfare decisions on their behalf at a future point, usually after the individual has lost capacity. For those who have already lost capacity, the courts can appoint an appropriate adult to manage decision making. An adult with capacity setting up a PoA is easier and cheaper than involving the courts after capacity has been lost. It is therefore highly recommended that those at risk of losing capacity (e.g. people with mild cognitive decline, or indeed any older adult), consider PoA for future use.

No test of capacity is applied to UK voting rights, provided the individual is registered and can express their choice. A person holding PoA, guardianship or similar cannot vote on their behalf[4]. To consent to a marriage, an individual is only required to have a simple understanding of the basic concept. They are not required to understand more complex details about financial and divorce rights. A similar, relatively simple level of understanding is required when making a will - the individual must understand the provisions, and recall what property they have, and any legal claims upon it. Contract law is typically determined on a case by case basis, and

whilst there are protections to guard against unscrupulous sales tactics, people with impaired capacity are vulnerable to financial exploitation. If a person is later judged to have already lost capacity when they entered into a business or marriage contract, or made a will, these are deemed void.

The legal interaction between mental capacity and criminal responsibility involves a delicate balancing act between promotion of personal autonomy and protection from inappropriate penal treatment. A detailed account of the moral and legal issues is beyond the scope of this review, and interested readers are directed to recent reviews on the topic, and concerns over the increasing number of prisoners with dementia[5–7].

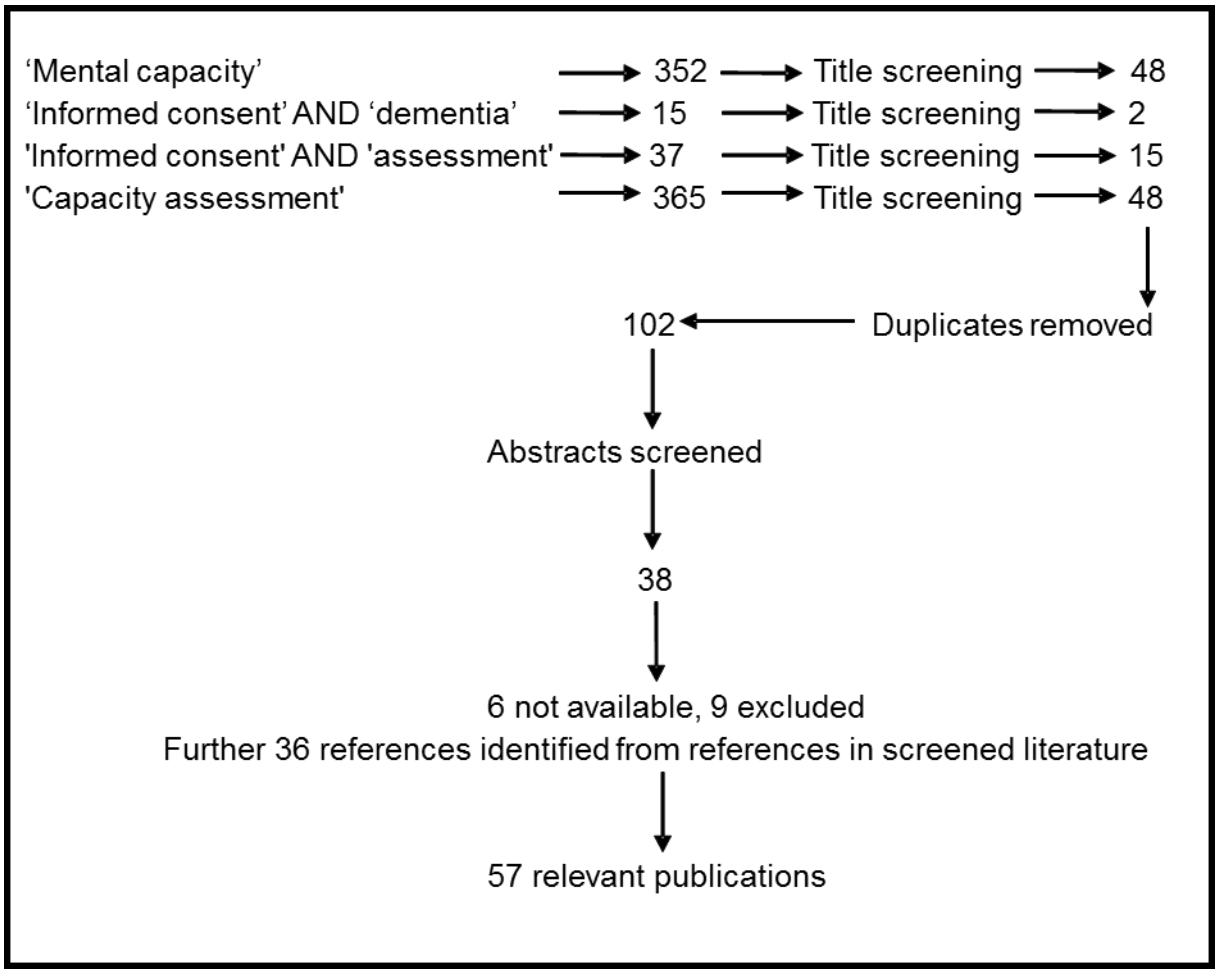
Evaluating whether an individual can make a decision in the real world is very challenging. Clinicians and researchers must objectively assess understanding and retention of relevant information, and ability to use information to make and express a choice. Multiple different tools have been developed to aid in capacity assessment. Some are aimed at specific patient groups or decision, whilst others are culture specific.

We reviewed published tools for assessing capacity. We compared different methods of capacity assessment, current research and the validity of different methods. This work focuses on methods of assessing capacity meeting UK legal requirements, and critically appraises current knowledge to identify what may be a gold standard approach towards the assessment of capacity. Internationally, many areas where capacity legislation has been enacted follow a similar model to the UK.

Search strategy and selection criteria.

A systemic review was undertaken of tools for the assessment of mental capacity. Searches were conducted between December 2016 and February 2017,limited to papers published in English after 2000. The following key words were used as search terms: 'mental capacity', 'informed consent', 'capacity assessment'. Papers were screened by title, then abstract. Publications dealing with capacity assessment and tools for evaluating capacity were selected. Additional relevant publications were identified from selected publications. Publications specific to the legal requirements of non-UK jurisdictions were excluded to allow proper cross-referencing with the relevant UK capacity legislation. Capacity assessments in any medical or psychiatric conditions and healthy adults were also included. Much of the literature has focused on how major mental health conditions impact on decision making, and it was felt that with due caution, insights from mental health research may be relevant to older adults with neurodegeneration.

Box 3. Summary of literature review findings (Pubmed; all searches limited to English language publications)



Results

Multiple instruments for assessing capacity exist, but none are universally accepted[8]. Most apply the following principles: does the patient understand the disease process and treatment options; do they appreciate that the disease and treatment are relevant to themselves; can they process relevant information and reason out a decision; can they express their choice. This is broadly consistent with UK legislation, but we should emphasise that UK law makes no requirement that a decision is reasonable or logical. Therefore, some tools are not compatible with UK law because they do not assess all the key principles defined therein, or they include a test of 'reasonableness'.

A key challenge in capacity research is the lack of an objective 'gold standard'. Capacity is traditionally evaluated during clinical assessments by psychiatrists and physicians, the reliability of which remains unclear[8]. Dedicated training in capacity concepts and legal definitions improves inter-rater reliability and reproducibility[9].In contrast, informal capacity estimates by healthcare staff and patient's relatives are unreliable compared to expert opinion and structured tool use[10].

Capacity rating tools typically do not give an overall rating or score, being designed as an adjunct to professional judgement, not a substitute. However, for clinicians and researchers looking for training in assessing capacity, or a tool to add to their clinical judgement, the final outcome is often more important than individual sub-scale measures.

Tools meeting UK legislative requirements are listed in Table 1. Most are a structured or semi-structured interview, where patients are given information about a real or hypothetical treatment scenario, then asked a series of questions to probe understanding, ability to use the information to inform a decision, and ability to express a decision. Some tools require that decision making be rational, which is not a UK requirement. Conversely, expression of choice is not emphasised in N.American literature, but is a key component of UK legislation. Therefore, several otherwise useful tools (e.g. Aid to Capacity Evaluation) do not meet UK requirements. Furthermore, some may require modification for certain groups. When the Structured Interview for Competency and Incompetency Assessment Testing and Ranking Inventory (SICIATRI) was used by Japanese patients discussing palliative care decisions two components had to be changed[11]. The original SICIATRI requires patients to take responsibility for healthcare decisions, which may be culturally inappropriate for older adults who expect decisions to be made by clinicians. Furthermore, the SICIATRI requires that people want to get better - which can be very relevant to people with mental health disorders who do not recognise that they are unwell, but is inappropriate for adults with a terminal illness. This does not negate the usefulness of SICIATRI, but it is important to recognise that some tools may require context-specific modification.

For everyday purposes (rather than use in research into capacity itself) toolkits that allow tailoring of the information to an individual decision are preferable. This allows decision specific assessments and simplification of information. It also avoids confusing adults with cognitive impairment by discussing hypothetical situations – a discussion that is arguably more complex than discussing a real-life, personally relevant decision.

Table 1. Capacity assessment tools fulfilling UK legal requirements. The ability to retain information sufficient to make a decision is specified in UK law: tools which require recapping of information were deemed to have met this standard.

Tool	Properties	Published samples	Duration
Assessment of Capacity for Everyday Decision Making[12]*	Semi-structured interview using 3 everyday decision scenarios. Developed for people with cognitive decline.	39 adults with mild to moderate cognitive impairment; 90 adults with AD, 92 with MCI. Good reliability, moderate to strong correlation with MacCAT-T.	15 minutes
Assessment of consent capacity for treatment[13]	Vignettes around planned treatment. Developed for adults with learning difficulties.	Limited published data available (no data on reliability available).	45 minutes
Capacity Assessment Tool [14]	Semi-structured interview. Tailored to specific treatment decision.	1 small pilot study of 20 psychiatric patients reported only.	Not stated
Competency to Consent to Treatment Instrument (CCTI) [15]*	2 hypothetical clinical vignettes, with detailed questioning and scoring of responses.	Validated in 79 AD and 20 Parkinson's disease patients. High inter-rater reliability. Normative data from healthy adults available (n=308, ages 19-86 years).	20 minutes
Decision assessment measure[16]	Standardized vignette regarding venepuncture.	Pilot study of 20 learning disabled adults, 21 with chronic mental health disorder. Good inter-rate reliability.	Not stated
Hopemont Capacity Assessment Interview (HCAI) [17]	2 standardized clinical vignettes.	High inter-rater reliability from a pilot study. Comparison with the CCTI & MacCAT-T found HCAI more likely to rate health controls as being impaired.	30-60 minutes
MacArthur Competence Assessment Tool-Clinical Research[18]	Structured interview, adaptable to different scenarios. Each aspect of capacity scored individually and cut-off scores specified.	Widely investigated in patients with dementia, mental health disorders and medical patients. High inter-rater reliability but lower test-retest reliability.	15-20 minutes
MacArthur Competence Assessment Tool–Treatment (MacCAT-T)[19]	Semi-structured interview. Adaptable to different scenarios	Data from adults with dementia and mental health disorders available. High inter-rater reliability.	15-20 minutes
Structured Interview for Competency/ Incompetency Assessment Testing and Ranking Inventory[11,20]	Structured interview. Adaptable to different scenarios. Requires that patients want to get better and want responsibility for decision making.	Good inter-rater reliability and validity in comparison to physician ratings (sample of 48 psychiatric and medical inpatients).	20 minutes

* Also requires that thought processes be rational.

Discussion

Neuropsychological underpinnings of capacity

Complex decision-making involves multiple cognitive domains. It is not surprising that correlating specific cognitive domains with capacity is challenging. Even when capacity is broken down into the basic components of understanding, weighing up choices, recalling information and expression of a choice, correlations with specific cognitive domains are variable, and of moderate strength. Similarly, correlations between capacity and global cognitive functioning are mixed. A score of 19 or less on the Mini-mental state examination (MMSE) robustly predicts incapacity, but a higher score does not guarantee capacity[21]. There is considerable heterogeneity within patient groups. Individuals scoring highly on neuropsychological tests may lack capacity, whilst others with significant cognitive impairments retain it[22]. One risk that may undermine the scope of capacity assessments is that they become a memory test – some involve extensive questioning, which draws heavily upon memory. Further work in people with neurodegeneration would be of great interest, particularly investigating the role amnesia plays in impaired capacity.

Overall, whilst global cognition correlates to some degree with capacity status, there are no definitive rules that can be applied. More complex decisions will require greater cognitive ability. Therefore, people with mild dementia may be able to make informed decisions about a simple, low risk, high benefit change to medication but not about a complex surgical procedure with a borderline risk/benefit ratio.

Even mild cognitive impairment can considerably impact on decisional capacity[16,21,23]. Understanding, retaining and using information are typically impaired, with expression of choice often remaining intact [24]. It has been suggested that expression of choice is less cognitively demanding than other aspects of decision making[23]. As dementia progresses there is a concomitant progressive loss of capacity. Clinicians should elicit opinions on future care at an early stage, to use in future ‘best interests’ decisions when an individual has lost capacity.

Cognitive fluctuation and capacity

Many conditions cause a fluctuating cognitive states, for example Lewy body disease and delirium. Capacity can vary day-to-day, or even hour-to-hour. Ways to optimise capacity include approaching an individual on a ‘good day’ (best identified by the patient, relatives or knowledgeable carers) and at a preferred time of day (e.g. avoiding the evening, when confusion may worsen).

Validity of capacity assessments

In some cases judging capacity is straightforward, whilst in others there may be disagreement between different clinicians, assessment tools or between tool and clinician[25].

Different tools have been developed for different patient groups and decision making scenarios – for example the University of California, San Diego Brief Assessment of Capacity to Consent (UBACC) is a brief screening tool to help junior researchers identify research participants who need further capacity assessment[26]. Others are tailored for people with dementia, learning difficulties, or mental health disorders. The local legal jurisdiction also influences capacity definition and assessment. It is therefore not surprising that there significant variability in tool design and results.

Moye et al. compared the MacCAT-T, CCTI and the HCAI for the assessment of people with mild to moderate dementia and matched controls[27]. All detected poorer understanding in individuals with dementia. When assessing reasoning, the MacCAT-T and CCTI identified impairments in the dementia group, whilst the HCAI did not. This highlights that different tools have different strengths and weaknesses. When considering which to use, the clinician or researcher should consider what their question is. When determining capacity to make a specific healthcare decision, the MacCAT-T, SICIATRI or CCTI may be useful. These can all be customised, and were designed for clinical use. The UBACC was derived from the MacCAT-T as a brief screening tool for clinical trial participants. As such it does not fully assess capacity, but is useful in screening for high-risk individuals who require further assessment, and has the advantage of being suitable for use by a graduate level researcher. Much longer, more detailed instruments exist for those conducting empirical research into capacity itself, such as the MacCAT-CR. A caveat however is that the more detailed interviews begin to examine the rationale and reasoning behind decision making – and such detail is not required under current UK legislation.

Dedicated instruments exist for people with major mental health disorders, where exploration of potentially abnormal beliefs is required. Groups such as those with anorexia are particularly challenging to assess, as they are typically high functioning individuals, and their illness is part of their personal identity. Patients may fail a test of capacity due to fixed, abnormal illness-related beliefs, rather than impaired understanding, recall or communication[9]. Decisions about mental capacity should never have a blanket approach, and professionals should tailor their methods to the individual and decision in question.

Capacity assessment tools vs. expert opinion

Traditionally decisions regarding competency ultimately rest with the responsible clinician or researcher, but how well different professionals agree with each other and structured assessments is unclear. Expert raters viewing the same footage of a structured assessment achieve high levels of inter-rater reliability [28]. However, clinical judgements made without using structured tool have lower reliability, particularly regarding people with dementia[29]. Informal ratings by the clinical team or relatives are much less reliable than either expert opinion or structured assessments[9]. This may reflect the information available – if understanding, recall

and decision-making are not specifically probed then clear-cut impairments may be missed. Health and social workers may assume capacity is present because either an individual agrees with the professional's plan, or they say 'yes' when asked if they understand. Such superficial assessments are inadequate and will miss both those lacking capacity, and those who with support (e.g. simplified information) could achieve capacity.

The discrepancy between the MacCAT-CR and expert opinion raises concerns as to whether expert opinion may over-estimate capacity. Alternatively, it may be that structured assessments (particularly research tools) are too stringent. Undue mnemonic demands should be avoided. The individual must be able to retain information long enough to make a decision, but longer term recall is not required, nor should they have to pass an exam to gain personal autonomy.

Whilst many studies are limited by small sample sizes and limited replication, they highlight variability in clinician judgment, and bring into question what should be our gold standard capacity assessment. It has been suggested that in clinical practice, clinicians may equate treatment refusal with lack of capacity and treatment acceptance with competency. Thus a capacity assessment may only occur if the patient refuses treatment. Whilst UK legislation presumes capacity to exist until demonstrated otherwise, we must be careful not to abandon the patient to their rights. Health and social care professionals must be vigilant to prevent neglect, particularly when individuals with complex neurodegenerative or neuropsychiatric conditions refuse interventions. There is a risk of serious harm to those who refuse medical or social care, and professionals who fail to conduct adequate and timely capacity assessments may be guilty of wilful neglect.

Assessing capacity is clearly more challenging in borderline cases. In such cases using structured tools or seeking a second opinion from a trained professional is sensible. Disagreement about capacity (either between professionals, or between staff and the patient or relatives) should prompt a detailed assessment and open discussion. This will allow people to be supported to have the highest level of capacity possible and permit those lacking capacity to have their views heard.

Social-cultural influences on capacity

There is an increasing awareness of the impact of social and cultural factors on decision-making. This includes religious beliefs, personal attitudes towards life-prolonging treatment, and cultural expectations that decisions will be taken by the healthcare team. Sensitive exploration of underlying beliefs and attitudes allows the clinical team to adapt to promote capacity. A refusal of or request for treatment may seem irrational to outsiders until the personal background is painted into the picture.

CONCLUSIONS

Defining and judging mental capacity requires a fine balance between patient autonomy and protection of vulnerable adults. UK legislation provides a clear framework for clinicians and researchers when assessing capacity. However, there are contrasting legal and clinical approaches: clinicians often view capacity as a gradient, whereas the legal approach is more dichotomous. With patient rights' reliant on judgments of decision-making capacity, it is imperative that such assessments are reliable and valid. The greatest challenge is the current lack of a gold standard. The complexity of capacity assessment means it is unlikely to be successfully reduced simply to a score on a memory test, or tick boxes in a questionnaire. Cognitive abilities, alongside patient emotions, values and experiences are all valid factors that contribute to decision-making. No current instrument is sufficiently flexible or broad in scope to consider individual and contextual factors in the assessment of capacity and for this reason expert judgment and due attention to patient values and narratives are essential. There is a pressing need for more research in this area but also for more widespread and thorough training for clinicians and researchers. There may even be scope to develop more standardised and universally agreed approaches to the assessment of capacity. Whilst there is a high level of awareness of UK capacity legislation amongst healthcare professionals and researchers, there is often a lack of understanding of the detailed components that make up capacity and hence more standardised approaches may be helpful. These must always be assessed in a sensitive and careful fashion, to both maximise a person's decision-making abilities and to protect those persons who are unable to make decisions for themselves.

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